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STICKLER INVOLVED PEOPLE
March 2013 NEWSLETTER

Coordinator's Comment

Normally, my favorite moments are when I get inspired and write to share my thoughts with you. However, the last months have been so busy that I am not sure I have any thoughts left to share or even time to think them. Please remember that stress is a killer of life. We have only so much time and to spend it 'in dilemma' is not fair to you personally or to your loved ones. Take a moment to stop and appreciate a kindness, a pretty scene, a nice smile. Or better yet, take out a moment to extend a kindness or a smile. We will all be better off for it!

Stickler DVDs

The 1st film is now available on <http://www.sticklervideo.org> , for free. The 2nd film, "Finding Hope" is now on the same website.

SIP SCHOLARSHIP

Dr. and Mrs. Stickler donated the start-up money for a fund to provide high school seniors, who have a diagnosis of Stickler syndrome, with a four year scholarship. Applications are available on line and due June 15 each year.

Please consider making a donation to the Scholarship fund. The new address for the scholarship fund is:

Stickler Involved People
Gunnar B. Stickler Scholarship Award
PO Box 775
Cologne, NJ 08213



SSAC

SIP Board is pleased to announce the formation of a new committee. April & Dan Murphy have graciously volunteered to lead the “Stickler Syndrome Awareness Committee” (SSAC). If you are interested in joining this important committee please contact Rick at Fifibish@aol.com.

The Stickler Syndrome Awareness Committee has gotten a new set of bracelets to increase awareness of Stickler syndrome. SO, they are in green and purple, our SIP colors, with our logo. If you are interested in purchasing bands, send \$20 for three bracelets to: Rick Bishop, 3921 Diamond Ridge Rd, Las Vegas, NV 89129

An easy way to help

IGIVE.com has sent Stickler Involved People over \$900 since it started. When you buy from the web, please remember to start with IGIVE.COM and make some money for us. There are some places that have special offers for IGIVE.COM subscribers. We get \$5 for each new person who places an order through IGIVE.COM. So, now is the time to look it over, subscribe, give Stickler Involved People as your cause, and place an order. You are helping SIP and may save yourself some money and time. REMEMBER IGIVE.COM as you finish your Christmas shopping!

Press Announcement

Lori Vickery sent this press announcement that the FDA approved the first retinal implant for adults with rare genetic eye disease.

http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm339824.htm#.UTYZ_0rvPxM.mailto

**Please discuss this with your ophthalmologist who knows
your eyes.**



Dr Ruth Liberfarb Announcement

Dr Ruth Liberfarb will retire as of March 14, 2013. She has been assured that the Stickler Syndrome Clinic will continue. We are trying to get her replacement to speak at the 2013 conference.

The clinic day may change, so check with Sandy. We wish Ruth the best and give her a GREAT THANKS for all she has done for Stickler Involved People and for all persons with Stickler syndrome.

There are far too few heroes in our lives and Dr Liberfarb is one!

STICKLER CLINIC

Patients will need to book the appointment with Sandy Massalski: 617-726-1561. The patient has to pre-register with Mass. General Hospital to give billing information, and to get a hospital number.

Dr Liberfarb's regularly scheduled clinic appointments are on Thursday afternoon from 1-5pm. The clinic can see 3- 4 people. The patient needs to submit medical records in advance. The Genetics Unit has a training program for physicians doing fellowships in Med. Genetics. Some of these "fellows" might want to participate in the clinic.

The clinic is not free, but it is a "dream come true" for persons with Stickler syndrome. Recently, I was able to answer someone that this is THE one place to visit with all the experts you need. Be sure to make your needs known when you call for an appointment.

2013 Conference News



In Las Vegas, we will use a slightly different format. We will meet on Friday night and all day Saturday. Lunch will be included with registration and will be a “working” lunch. There will be no program organized on Sunday. Saturday evening and Sunday activities are on your own.

Another difference will be that room reservations will be limited. A contract has been signed with the Embassy Suites on Paradise Road which is close to the airport. So, you can make reservations now at www.eslvcc.com. Be sure to request the Stickler Conference rate.

STICKLER SURVEYS

You have the opportunity to help two research projects about Stickler syndrome, using just a few minutes of your time.

One is from Eline Van Oostrum, an 18 year old with Stickler syndrome. The link is

<https://docs.google.com/spreadsheet/viewform?fromEmail=3Dtrue&formkey=3Dd=>

She has had 90 responses so far and will get data to us as soon as possible. This is a school project.



The second survey wants participants with or without dizziness. We need information from BOTH those affected by dizziness and those not affected by dizziness. The request is that you respond as a person affected by Stickler syndrome. Please remember this if you are a parent answering for a child.

The survey is entitled "Balance and Dizziness in Stickler syndrome" and wants input from all those affected by Stickler syndrome, even if they feel their balance or dizziness is not an issue.

Once complete and analyzed, SIP will distribute any trends identified. This is the link to the survey: <http://www.surveymonkey.com/s/LDX88V2>

REMINDER

Please note that Jon Rodis, a specialist in disabilities, and his wife, a disability lawyer, have committed to joins us in Las Vegas!

We will also have a round table discussion about where to take Stickler Involved People from here.



**SEE YOU IN VEGAS BABY!!
JULY 12-13, 2013**